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ABSTRACT

This report begins with discussion of several issues in the field of quality assurance in residential services for individuals with developmental disabilities. The issues include definitions of key terms, the role of ideology, major types of quality assurance, and dimensions of quality assurance. The report takes the position that primary values include integration, consumer participation, choice, and a focus on the essence of "homeness." An annotated bibliography of instruments designed to review program quality describes two instruments developed by national accreditation bodies, eight published systems for assessing/assuring program quality, and 17 additional references on quality assurance systems. An annotated bibliography of measures of individual integration offers descriptions and comments on 11 check lists, interview schedules, survey forms, and other rating scales. Appendixes contain a reprint of "The Community Imperative: A Refutation of All Arguments in Support of Institutionalizing Anybody Because of Mental Retardation" (a statement by the Center on Human Policy of Syracuse University); a statement in support of families and their children; an article by Hank Bersani, Jr., titled "Making Sure a House Is Still a Home"; and information on ensuring quality services. (JDD)

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Center on Human Policy

ASSURING RESIDENTIAL QUALITY:
ISSUES, APPROACHES AND
INSTRUMENTS

Assuring Residential Quality:
Issues, Approaches and Instruments

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PART I

MAJOR ISSUES IN QUALITY ASSURANCE

This report addresses several recurring issues in the field of quality assurance. These include definitions of key terms, the role of ideology, major types of quality assurance, and dimensions of quality assurance.

Definitions of Terms.

A number of terms are used, often interchangeably, in discussions of quality assurance. These terms are defined below in ways that represent their use in this report.

Assurance. The act of "assurance," or "to assure" means to make secure or stable, to safeguard. In this sense, we use quality assurance mechanisms to secure quality, to make that quality stable, and to safeguard that quality over time.

Quality. Definitions of "quality" frequently include: the essential nature of something, a trait or characteristic, or superiority. For our purposes, we can consider two of these three meanings: quality can mean either an essential nature of something, or superiority. Because the focus of this report is on the quality assurance of "residential settings" (the homes where people live), we may wish to "assure" that the residential options have the essential nature of "homeness." The second meaning of quality refers to superiority, and so we seek to assure that the homes in which people live are of a superior nature. In this sense, quality assurance goes beyond compliance

with minimal standards of adequacy, and rather looks to a higher (and often more difficult to measure) standard of excellence or superiority.

The role of values.

By definition, the process of quality assurance involves promoting or insuring a certain standard of quality. However, determining what is "quality" is an art form as well as a science. How we assure quality will depend on how we define quality, and how we define quality will be determined by our values. The following are some examples of values that can effect decisions about quality assurance.

House vs. program. There is an ongoing conflict in residential services between these two extremes. On one hand is the pressure to be a "rehabilitation program"; to teach people new skills, to develop personal independence, to increase adaptive behaviors, to move up to a new skill level. On the other hand is the concern to make the residence more than just a facility or a training program. We seek to make the house a true home, a place where an individual (sometimes called the "resident" or "client") makes his/her home. Arguments can be made for either perspective, and most "residential programs" end up operating as some type of compromise between these two positions. Clearly, these conflicting values have a major effect on the type of quality assurance that is implemented.

If the value that is selected is that of "program" and striving to meet goals reflecting personal development, then

quality assurance measures will focus on "client progress." Outcome measures such as increased scores on standardized intelligence tests or adaptive behavior scales will be viewed as indicators of success. Likewise, lists of goals accomplished, and skills learned will be viewed as quantitative indicators of quality.

In contrast, our perspective is that the residence is first and foremost a home. While we all do learn, grow and develop in our homes, our primary interests are around the quality of life that the home offers. From this perspective, "quality" is determined more by the sort of indicators that we each use to evaluate our own homes and life styles. For ourselves we value privacy: both modesty and time alone. We value having our own space to use and decorate as we wish. We value making our own choices, even if the consequences are not always in our best interest. We also value abstract ideas that seem antithetical to mental retardation: wealth, health, power, ownership, status, dignity and respect. Finally, most of us value our friends and our relationships to others; freely given reciprocal relationships with others including those who do not live with us. If our value is to make the residence a home and our view of quality is to offer people the same life conditions that we all value, then the quality assurance system must look beyond measures of individual growth and development; we must turn to indicators of presence and participation in the community,

developing interpersonal relationships with others (who are not handicapped), personal choice and self-determination.

The value bias of the service provision system will be reflected in the answers to some basic questions that can never be determined totally by research or science. These questions can only be answered by the application of a well-defined value system. Some of these questions are:

Where should people live?
What is the role of institutions?
Who is ultimately responsible for program quality?
How good is good enough?
What makes a house a home?

Acknowledgment of Values

Much of quality assurance is quite sophisticated, and we should not minimize the need for a sophisticated statewide system. On the other hand there is an aspect of quality assurance that is very straightforward. By recognizing the importance of values, and realizing that we each have a set of values for our own lives, we can make a start on quality assurance. In effect, it is legitimate for one to say "I may not be an expert on quality assurance, but I know what I like." Burton Blatt used to say "You don't need a Ph.D. to know when you've stepped in a pile of dung." The point is this: if our value system is to offer quality home living to individuals, then our commonly held values of privacy, self-determination, and ownership are essential aspects of quality. In that sense, we are all experts because we know what we want for ourselves and our loved ones.

A final consideration about values is that they must be articulated into a cohesive system. That system then becomes the road map for day to day decision making. At the Center on Human Policy, through our Research and Training Center on Community Integration and our Community Integration Project, we have developed a brief list of statements that reflect our philosophy. While this list is not meant to be exhaustive, in the frame of just six statements, the basis of our value system becomes clear:

- * People with developmental disabilities, including those with the most severe disabilities, should be served in their home communities.
- * The size of community living arrangements should reflect the size of other homes located in the neighborhood that are populated by other people who are not handicapped.
- * Services should support people in typical homes, real jobs, and ordinary community environments.
- * Services should foster the development of meaningful, reciprocal relationships with other community members.
- * Services should foster the development of practical life skills, and promote the use of those skills in functional environments.
- * People with disabilities themselves, their family members, and the general public must be involved in the design, operation, and monitoring of services.

(Adapted from: Taylor, Racino,
Knoll and Lutfiyya, 1987)

In addition, the Center on Human Policy has developed two other major statements of our value basis. These two documents are "The Community Imperative" (Appendix A) and "A statement in support of families" (Appendix B). Once values are refined and articulated, they become the basis for future action.

Major forms of quality assurance

Quality assurance may take many forms. The following is a list of common types of quality assurance approaches. Each method has its own benefits, and there is no single "best" approach. Rather, there is a benefit in using several of the approaches simultaneously to create a multi-dimensional, systematic approach to quality assurance. Different types of quality assurance involve different factors: administrators, professionals, residents, advocates, case managers, family members, and the general public.

Certification. The most prominent example of certification is Medicaid certification to receive Title XIX funds as an Intermediate Care Facility (ICF). An agency must conform to federal standards to be eligible for funding which is contingent on certification.

Licensure. Assuring quality by licensing is usually a function of the state. The state sets minimum standards which a program must meet in order to be licensed by the state. Usually receipt of state funding is tied to licensing. In some states there is also "certification" by one body (i.e., Office of Mental Retardation) and licensure by another (i.e., Health Department).

Accreditation. In theory, a program seeks accreditation voluntarily; however, many states now require accreditation as a part of their licensure review. The most common accreditation programs today are the American Accreditation Council for Developmental Disabilities (ACDD) and the Council for Accreditation of Rehabilitation Facilities (CARF).

County Review. In many states, there is a great deal of county control over the development and operation of services. In these states, there is a level of quality assurance that occurs at the county level. In some cases counties may have a formal licensing function, in other cases they perform a lesser review function.

Case Management. Although case management is often considered to be a service itself, it can also be considered as a mechanism to assure the quality of residential services. Case management functions best as a quality assurance mechanism where there is a minimal conflict of interest for the case manager and where the size of case load is small enough for the case manager to develop intimate knowledge of the person and his wishes and needs. If a case manager is directly employed by the same agency serving an individual, the strong conflict of interest will be difficult to overcome. In order for case managers to make a significant contribution to quality assurance, they must be independent of the agency providing service to the consumer.

Peer Review. Agencies may have formal or informal arrangements whereby one agency provides a review of a second agency in return for its own review by that (or another) agency. Peer reviews have a distinct advantage in that staff and administrators from another residential service may have valuable information on a variety of practical matters within a region. On the other hand, there is a clear and present danger that the peer reviews will become incestuous and that agencies will "go easy" on each other.

Internal Review. In this instance, an agency makes a commitment to review its own programs on some regular basis. As with peer review, there are potential benefits to having people who are well versed in the issues conduct the assessment. Many of the instruments reviewed in Part II and Part III are appropriate for internal review. In particular, the Personal Integration Inventory reviewed in Part III is a useful tool for internal review. This issue is also addressed by the Safeguards system used in Nebraska's Region V reviewed in Part II.

External Review. Several instruments have been designed specifically for use in external reviews. Such reviews may be carried out by funding bodies, supervisory boards, or external consultants. Several of the tools reviewed in Part II are appropriate for such an evaluation, such as PASS and ANDI. External reviews provide an excellent opportunity to involve people with disabilities in the review team.

Resident Governance Committee. Because the persons who live in a residential service are the ultimate consumers of that service, a good quality assurance system must include feedback from those consumers. This is a type of internal review. In the general public, consumer feedback might happen through the form of a tenants association. The resident governance committee is a natural extension of that approach. A state-wide quality assurance system should require or at least support resident governance committees.

Citizen Advocacy. Citizen advocacy is a process whereby a non-handicapped citizen, who is paired up with an individual with a disability, volunteers to represent the rights, needs and interests of the person with a disability as if they were his/her own. A citizen advocate offers an informal but frequent type of monitoring. Each time the advocate speaks to or visits a consumer in residence, the advocate "monitors" the quality of the service the consumer is receiving. Frequent visits from a number of citizen advocates can be a powerful incentive for quality because of the public visibility associated with citizen volunteers.

Citizen Monitoring. More formal than the monitoring that occurs with citizen advocacy, citizen monitoring projects involve the use of specific monitoring approaches or tools to review program quality on a regular basis. A distinct advantage of citizen-based quality assurance is the fact that citizens (neighbors, friends and family members and people with disabilities) view residences from a much different perspective than most professionals. Citizen review teams are especially well suited to determine the living quality in a home as opposed to assuring minimal compliance with professional standards. The effectiveness of citizen reviews can be greatly enhanced by a formal endorsement from state or county officials. Citizen monitoring teams can function as internal monitors (as in Michigan) or as external monitors (as in Ohio).

Legal Review. This includes both the involvement of Protection and Advocacy services and in many states specialized Legal Rights Services which are made available free of charge to people who meet low income guidelines. Both types of agencies might conduct their own reviews of programs, usually with a focus on the legal rights of the consumers. In isolation, these reviews might only respond to crisis situations. In conjunction with other approaches, legal reviews make a significant contribution to quality.

It is worth reiterating: no one of these forms is "best" and one or even a few types of monitoring is not sufficient to truly assure quality. Quality assurance requires the systematic application of a variety of measures and techniques which together can assure quality.

The combination of methods must reflect the various dimensions of quality assurance discussed in the next section. Suggestions on insuring quality services are discussed by Taylor, Racino, Knoll and Lutfiyya (1987), and are included in Appendix D of this report.

Dimensions of quality assurance

We can consider quality assurance to have several dimensions each with a range between two extremes. These include the source of the monitoring (internal vs. external), the formality of the assessment (informal vs. formal), the nature of the data collected (quantitative vs. qualitative), the nature of the feedback (summative vs. formative), and the program aspect being

evaluated (input-process-outcome). With these dimensions, as with the various methods of quality assurance, there is no "right" answer. Any quality assurance system will address different aspects of each dimension. A complete quality assurance system will address each of the dimensions, across the continuum of choices for each dimension.

Internal vs. external assessment. An external assessment is one which comes from outside the agency that is being assessed. Licensure, certification, accreditation, state assessment, etc. are all examples of external assessment. At the other extreme, internal assessments are those which originate within the program or agency. Internal assessments include feedback from residence governance committees as well as reviews conducted by staff, administrators, or advisory committees. External approaches have the benefit of being more objective, and require accountability to an external body which minimizes conflict of interest. Internal review has the advantage of coming from the people who know the agency or program the best and who may be able to offer more concrete suggestions for change. A balanced system will include several external mechanisms, and at least a few internal review mechanisms. Many of the instruments described in Parts II and III can be used internally as well as externally.

Formal vs. informal. A quick review of the various forms of quality assurance discussed shows the tremendous variety across this dimension. Licensure, certification and accreditation are quite formal. They are applied by designated bodies, on a regular basis, in very controlled situations. At the other

extreme is the type of quality assurance that comes from informal visits by citizen advocates and the general public. In between these two extremes are citizen review teams, which often do not have the formal status of a certification review, but are more organized than the day to day visitations of a citizen advocate. It is important that the quality assurance system not focus only on either extreme. Formal assessments offer comparisons across programs, some assurance of minimal compliance to broad-based standards, etc. On the other hand, the less formal methods afford a more on-going type of monitoring, and provide opportunities for involvement of non-professionals.

Quantitative vs. qualitative. The feedback to the program can take on two basic forms: a numerical score (quantitative) or a descriptive report (qualitative). Again, there are advantages to each approach. Scores allow for easy comparisons between programs, and of the same program over time. When reliable and valid, scores can represent a distilled version of the data, reducing the evaluation information to a single score or a set of scores. On the other hand, anyone who has ever received a grade, or had their IQ tested, is aware of the weakness of scores; the information is so distilled that much of the meaning is lost, and there is often insufficient information available to interpret the score. Descriptive reports are a viable alternative. Just as many students would prefer a written evaluation for a semester's work rather than a single grade or score, and just as a description of an individual's abilities and disabilities offers more information than an IQ score or an adaptive behavior

score, so too, a descriptive report of program quality offers information not available from a simple score. Among the various types of quality assurance outlined, there is a wide variety in the types of reporting used. Often, the functions of licensure, certification, and accreditation focus on quantitative assessment. A series of subscale scales are totaled, and a final decision is made to certify or not, accredit or not, license or not.

By contrast, some of the citizen monitoring approaches, such as the ARC-Ohio system (described in Part II and Appendix C, generate only a descriptive report, with no scores at all. At a point between these two extremes are assessments such as Program Analysis of Service Systems (PASS 3) (also described in Part II), which, when used as directed, generates an extensive system of subscores and a total score, and also produces a detailed report with a variety of recommendations for the agency. Qualitative and quantitative reporting are not mutually exclusive, and there is nothing to prevent combining a written report with a score or a grade, to allow the agency to respond to concerns. This is linked to the next dimension, formative vs. summative evaluations.

Formative vs. summative. At one extreme, summative evaluations are those which merely report the results of the assessment (pass, fail, or a descriptive analysis of the status of the program). At the other extreme are formative types of evaluation which tend to occur on an on-going basis, and offer suggestions for improvement. For example, the exam that lawyers

take to be admitted to the bar is strictly summative; applicants are informed only of their scores and whether or not they passed. Formative assessment is more interactive. The individual (or program or agency) receives feedback at regular intervals with suggestions on how to improve performance. Part of subsequent evaluations includes an evaluation of how well previous feedback has been utilized. Citizen review projects, like that used in Macomb-Oakland and Ohio, usually have a high visibility, making frequent visits. Monitors make suggestions for improvements and on subsequent visits expect to see those suggestions implemented.

Input-process-outcome assessments. Traditionally, rehabilitation programs have been evaluated in one or more of these three areas. Input evaluations examine the allocation of resources applied to a given problem. For example, a measure of a state's commitment to deinstitutionalization could be the percentage of state funds that are spent on institutional vs. community services. Quality assurance measures of input focus on the numbers of staff, or amount of money spent in various aspects of a program. These figures can often be informative; however, they are inadequate as measures of quality unless presented in the context of other types of measures as well. Input measures also address a program's potential to perform various tasks; for example, a program review might explore whether an agency has the capacity to provide psychological or physical therapy services to

individuals who might need those services. A purely "input" assessment of this sort would not address the quality of that service once delivered.

Process evaluations ask more about the actual delivery of those services and the nature of how they were delivered. For example, an input evaluation might ask the size of the budget allotment for recreation; a process evaluation would ask how the money was actually spent, and if the recreation was integrated or segregated. Concerns of normalization, integration, etc., would be addressed under the heading of "process".

Outcome evaluations, as the name implies, look at the outcomes of various activities. There is a growing movement in the field of mental retardation and developmental disabilities to become more outcome oriented in a belief that outcome measures are the most objective measure of quality. Recently the federal Health Care Financing Administration (HCFA) developed outcome measures for Medicaid Certification. A specific example of a proposed measure points out the potential problems with outcome measures. One proposed outcome measure was the number of people in a program who do actually vote. The implication is that the process of offering the opportunity to vote is not sufficient; unless the outcome of voting occurs, the objective has not been met. This conflicts with goals to promote values in quality assurance such as self-determination, personal choice, etc. An outcome measure of "voting" does not allow such choices. Outcome measures can be quite useful, but they must be written with great care. Often the measure which is most observable and measurable

(number of residents actually voting) is also the least meaningful. A quality assurance system must resist the temptation to measure those things which are the most easily measured without regard for the importance of those outcomes in the lives of consumers for whom we are attempting to assure quality.

Summary

To summarize the material covered this far, we have discussed five major issues in quality assurance: definition of terms; role of values, acknowledgment of values; major forms of quality assurance; and dimensions of quality. How we define and measure quality is a function of values, and the position of this report is that primary values include: integration, consumer participation, choice, and a focus on the essence of "homeness."

We discussed ten forms of quality assurance and five dimensions across which these forms must be applied. Quality assurance does not rest on a single instrument, nor does it reside in a particular office. Quality assurance requires a state-wide commitment with diverse activities at several levels.

PART II

Annotated Bibliography of Instruments Designed
to Review Program Quality

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Annotated Bibliography of Instruments Designed to Review Program Quality

I. Instruments Developed by National Accreditation Bodies.

These instruments are based on national standards which are widely recognized and commonly used. In each case, there is a fee involved in obtaining a program review using these standards and if the standards are met, the agency or program is "accredited" by the organization that sponsors the system. An increasing number of states are requiring that programs be accredited by one of these systems, although an increasing number of advocates have expressed concern for the use of these standards. Criticism focuses on concerns that the systems are "paper bound", requiring a great deal of paper work, and often demonstrating only paper compliance with the standards. A second criticism is that the standards tend to encourage mediocrity in that they are interpreted as minimal standards, and seek minimal compliance, rather than proposing standards for excellence. Supporters deny these charges, and argue in favor of the benefits of national standards and norms rather than having state by state or agency by agency development of standards.

- a) Commission on Accreditation of Rehabilitation Facilities (CARF). Standards Manual for Organizations Serving People with Disabilities.

The most recent CARF standards were published in 1987.

These standards are not specific to residential facilities, and are commonly used to accredit rehabilitation facilities and programs such as sheltered workshops or supported

employment programs, as well as residential settings. The 1987 Standards Manual groups standards into 3 groups: standards for the organization; standards for all programs; and standards for individual programs or services. Information is available through CARF, 2500 North Pontano Road, Tucson, AZ 85715, (602) 886-8575.

- b) The Accreditation Council on Services for People with Developmental Disabilities. Standards for Services for People with Developmental Disabilities

Formerly the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons (AC/MRDD), but with the 1987 standards, the mental retardation focus has been dropped. ACDD admits that the current standards are "facility based" and efforts are currently under way to develop accreditation standards for what they call "Community Support Services", that is, services that are not necessarily tied to a facility. Mindful of previous criticism that there was an insufficient value base in the standards, the 1987 standards make a significant attempt to address current values, including a section which discusses the rights of individuals, confidentiality, normalization, age-appropriateness, and least restriction. An information packet is available from ACDD by writing to: 120 Boylston St., Suite 202, Boston, MA 02116.

II. Published Systems for Assessing/Assuring Program Quality

These instruments are published approaches to monitoring and assuring program quality. Some are designed specifically to require sophisticated training and are more commonly used by professional providers and advocates. Others have been developed specifically to be used by consumers, parents, or the general public with little or no training.

- a) Wolfensberger, W. & Glenn, L. (1975). Program analysis of service systems (PASS 3) Handbook and Field Manual. National Institute on Mental Retardation, Toronto.

This two volume set is designed to be used together, and in conjunction with a minimum of five days of training. PASS is designed to be an evaluation tool for all types of human services, rather than being specific to mental retardation services or residential services. PASS is based on the principle of normalization. The instrument is quite extensive, requiring several days of effort from a team of reviewers to evaluate a program. The process results in a score, although emphasis is given to writing a report based on the findings. Available through the Training Institute for Human Planning, 805 South Crouse Avenue, Syracuse, NY 13244.

- b) Wolfensberger, W., & Thomas, S. (1983). PASSING: Program Analysis of services system implementation of normalization goals: Normalization criteria and ratings manual. (2nd Ed.) Toronto: National Institute on Mental Retardation.

PASSING is an outgrowth of PASS 3 (described above). It is intended to be more easily used by parents, consumers, and the general public, although the text is actually much longer and more complicated. The instrument is intended to be used in conjunction with extensive training as in PASS 3. PASSING is designed to be used in full to generate a total score, although the individual ratings are able to be used independently. The values in PASSING reflect the changing conceptualization of normalization and the movement toward the conceptualization of Social Role Valorization.

Available through The G. Allan Roeher Institute (formerly the National Institute on Mental Retardation), Kinsmen Building, 4700 Keele Street, York University, Downsview, ON M3J 1P3, Canada.

- c) Bogdan, B. (1974). Observing in institutions. Center on Human Policy, Syracuse, NY.

This publication is one of a series titled "Notes from the Center", and its focus, as the title indicates, is on mental retardation institutional settings. The guidelines are composed of a series of questions clustered into 17 categories. There is no scoring system or reporting mechanism. The book is designed to serve as a guide for careful observation while touring a setting. Still useful for structured observation in institutional settings. Can

be used with no training. Available from the Center on Human Policy, 200 Huntington Hall, Syracuse, NY 13244-2340 for \$1.00 plus 10% postage and handling.

- d) Nebraska Region V Mental Retardations Services (n.d.).
Safeguards: A system for monitoring service quality.
 Lincoln, NE.

The residential services in Region V, Nebraska uses a monitoring system which has six components including internal and external review procedures. Various review procedures are described ranging from fire safety inspections to self-advocacy reviews. For each component, the guidelines list the responsibilities of the region, the focus of the component, the procedures to be followed, the frequency of the activity, how results are to be disseminated, and the rationale for the procedure. There is a great deal of information packed into twenty pages in this publication. It is not an evaluation instrument itself, but rather presents guidelines on the use of various types of evaluations. Available through Pegion V Mental Retardation Services, Trabert Hall, 2201 South 11th, Lincoln, NE 68502.

- e) Association for the Macomb-Oakland Regional Center (n.d.).
Monitoring committee guidelines. Mt. Clemens, MI.

Although this instrument has not been formally published, it has been widely circulated and is quite well known for two reasons. First, it is an intricate part of the success of the Macomb-Oakland Regional Center services, which have

received a great deal of favorable attention over the past decade. Second, it represents the first attempt to organize a formal monitoring system that is based on the efforts of parents rather than professionals. An article describing the development of the process is published in the December 1985 issue of The Exceptional Parent. AMORC provides orientation sessions for new monitors, but the instrument can be used without training. Available through Macomb-Oakland Regional Center, 16200 Nineteen Mile Road, Mt. Clemens, MI 48044.

- f) Bersani, H. (1984). Monitoring community residences: Handbook and guidelines. ARC-Ohio: Columbus, OH.

This two volume set is designed to be used by parents and private citizens. The guidelines were developed to be used after an eight hour training session, although it is possible to use the system with little or no training. The questions are open ended, and are specific to group homes. No score is offered, rather the training and the material in the Handbook are aimed at monitors writing a brief report of salient findings. The system is based in normalization, but is designed to be much less complex than other normalization related approaches. A typical monitoring effort requires half a day of visiting the home, and another half a day in team discussion and report writing. A description of the ARC-Ohio system was published in the March 1986 issue of

Transition Summary, published by the National Information Center for Handicapped Children and Youth. Available through ARC-Ohio, 360 South Third Street, Suite 101, Columbus, OH 43215.

- g) Flynn, A., & Weiss, S. (1977). A normalization and development instrument (2nd Ed.) (ANDI). Sacramento, CA.

Based on PASS, and JCAH standards (both described in this list), it is designed to be used either as an internal review by a program or agency, or as an external review by advocates. ANDI is easier to use than PASS or accreditation standards, but it is still quite complicated. This has prompted the development of a consumer edition (described below). Available through ANDI, P.O. Box 60964, Sacramento, CA 95860.

- i) Allen, W., & Gardner, N. (1983). An ANDI workbook for looking at places people live and work. Napa, CA.

This abbreviated version of ANDI is intended to be used directly by people who are themselves consumers of mental retardation services. The introduction explains that this workbook can be used by a consumer and staff to look at the consumers own program, or to be used by an outside team (external evaluators) to examine the quality of a program. Available through Area IV Developmental Disabilities Board, 1700 Second Street, Suite 384, Napa, CA 94559.

III. Additional References on Quality Assurance Systems

These references do not contain specific assessment instruments; however, they do contain valuable information on quality assurance.

- a) Minnesota Department of Human Services, Mental Retardation Division. (1987). Minnesota state plan for services to persons with mental retardation and related conditions: January 15, 1987 to January 14, 1987.

Includes sections on implementing values on a system-wide basis, quality assurance, and external monitoring of services. A section on values describes normalization, community integration, supporting natural homes, age appropriateness, real jobs, real homes, real schools. Available through the Mental Retardation Division, Department of Human Services, Central Office Building, 658 Cedar Street, St. Paul, MN 55155.

- b) Commonwealth of Pennsylvania, Department of Public Welfare. (1986). Quality assurance in community mental retardation programs.

This statewide policy on quality assurance defines systems that are most likely to provide "quality" as systems which meet 15 criterion, including:

- * Clients achieve maximal growth and development
- * An informed and active citizenry supports and monitors service delivery
- * An annual evaluation of each county mental retardation program is conducted.

Available through Office of Mental Retardation, Office of Program and Policy Development, 302 Health and Welfare Building, Harrisburg, PA 17120.

- c) City of Philadelphia, Department of Public Health (1986). Memorandum on quality assurance.

Both this and the above policy for the state of Pennsylvania were inspired by the massive deinstitutionalization in that state. The city of Philadelphia, which has received large numbers of people returned to the community from Pennhurst, has developed this policy statement to move beyond minimal community placement to true quality. In addition to reaffirming the state policy, the city policy offers eight elements of "minimal" quality assurance plans including:

- * Standards must be flexible
- * All quality assurance efforts must be correlated to individual needs.

Available through Department of Public Health, Office of Mental Retardation, One Reading Center, 1101 Market Street, 7th Floor, Philadelphia, PA 19107-2907.

- d) New Hampshire Area Agency for Developmental Services, Region VI. (n.d.). Quality assurance policy.

Begins with a statement of values, and definitions of the goals and process of quality assurance. Also includes a schema for quality assurance evaluations. Available through

Region VI Area Agency for Developmental Services, Inc.,
Suite 22, Harris Pond, 32 Daniel Webster, Merrimack, NH
03054.

- e) Conroy, J., Feinstein, C., & Lemanowicz, J. (1986).
Principles of quality assurance: Recommendations for
action in Pennsylvania (Draft #3). Temple University
Developmental Disabilities Center/UAF. Philadelphia,
PA.

This is a very well-organized document that offers the
reader a great deal of information in an easy to use
format. The authors list the properties of an "ideal"
quality assurance system including ten principles and twelve
kinds of monitoring. Available through the Developmental
Disabilities Center, Ritter Hall Annex 963, 13th and
Columbia Avenues, Philadelphia, PA 19122.

- f) Human Services Research Institute (1984). Assessing and
enhancing the quality of human services: A guide for
the human services field (Executive Summary).

This summary of a much larger report offers a great deal of
information in relatively few pages. Sections include:

- * General problems and issues
- * Quality measurement
- * Quality control
- * Quality assurance matrix

Available through Human Services Research Institute, 2336
Massachusetts Avenue, Cambridge, MA 02140.

- g) The Resident Home for the Mentally Retarded (1984). A families guide to evaluating community residential services.

Developed by a residential service agency, this four page document lists eight aspects of a program that parents should examine when evaluating a residential program.

Available through RHMR, 3030 West Fork Road, Cincinnati, OH 45208.

- h) Keith, K., Schalock, R., & Hoffman, K. (1986). Quality of life: Measurement and Programmatic Implications.

Stresses the need for objective, reliable data to make administrative decisions. Offers a 28 item instrument with reliability scores for individual items, and a sophisticated factor analysis. The instrument can be used without worrying about the statistical information which is reported in great detail for the use of researchers. Available through Region V Mental Retardation Services, P.O. Box 614, 808 Eighth Corso, Nebraska City, NE 68410.

- i) O'Brien, J. (1978). Monitoring service quality: A manual for voluntary associations (Test Edition).

Offers useful information about quality assurance. Most interesting is a division of quality assurance activities into two categories: quality assurance which can be initiated by an agency on its own initiative; and quality assurance that requires a public mandate. This distinction

can be useful to advocates to understand when to push the system for greater quality assurance efforts. Available through John O'Brien, 58 Willowick Drive, Decatur, GA 30338.

- j) O'Brien, J. (n.d.). Notes on quality assurance. Responsive Systems Associates, Decatur, GA.

Discusses the responsibilities of "the system" and individual service agencies in providing and maintaining quality services. Available through John O'Brien, 58 Willowick Drive, Decatur, GA 30338.

- k) Bradley, V. (n.d.). Ensuring the quality of services for persons with mental retardation. Human Services Research Institute.

Describes the importance of quality assurance, defines quality, critiques existing methods of quality assurance, and offers recommendations for a workable quality assurance scheme. Available through Human Services Research Institute, 2336 Massachusetts Avenue, Cambridge, MA 02140.

- l) McWhorter, A., & Kappel, B. (1984). Mandate for quality Vol. 1, Building on experience; Vol. II, Missing the mark. Toronto: National Institute on Mental Retardation.

This two volume set analyses the experience of three U. S. state systems, and then attempts to apply the principles learned in those states to the Canadian province of

Ontario. Available through The G. Allan Roeher Institute (formerly the National Institute on Mental Retardation), Kinsmen Building, 4700 Keele Street, York University, Downsview, ON, M3J 1P3, Canada.

- m) Wisconsin Coalition for Advocacy. (n.d.). Guidelines for service selection and development.

Only two pages long, this checklist is intended to be a "thumbnail" outline of the factors to be considered in the selection of a site for service, or in the planning/development of that service. Areas addressed include the physical setting, the grouping of consumers, the relationships among people in the setting, and the symbols or imagery attached to the program. It is best used to assess plans for a program that has not yet begun. Available through the Wisconsin Coalition for Advocacy, 16 North Carroll, Suite 400, Madison, WI 53703.

- n) Onondaga County Residential Service Cluster. (n.d.) Citizen review process for community residential settings.

Designed to be used by citizen volunteers after an evening orientation session. Uses several pages of open-ended questions to address areas such as the property and neighborhood, the interior of the residence, residents' rights, etc. Available through Onondaga County Department of Mental Health, 421 Montgomery Street, Tenth Floor, Syracuse, NY 13202.

- o) Minnesota Governor's Planning Council on Developmental Disabilities. (1987, July). Guidelines for quality individual plans.

These guidelines are printed on a single page of heavy stock paper and widely circulated by the Council. It offers clear and concise information on a 5 point evaluation of the quality of a plan. Is it: age appropriate, community referenced, functional and generalized; and based on an individual's preferences? Also included are several suggested readings. Available through the Minnesota Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155.

- p) Minnesota Governor's Planning Council on Developmental Disabilities. (n.d.). Test your IQ: Integration quotient.

Printed as the flyer previously mentioned, these guidelines are aimed at organizations serving people with developmental disabilities. Items are aimed at the administration of the service, the individuals who are served, and the environment of the agency. Available through the Minnesota Governor's Planning Council on Developmental Disabilities, State Planning Agency, 300 Centennial Office Building, 658 Cedar Street, St. Paul, MN 55155.

- q) University of Oregon. (1985). Speaking up and speaking out to make services better. In Speaking up and speaking out: An international self-advocacy movement.

This book reports on a self-advocacy conference held in 1984, and Chapter 5 reports on a workshop led by John O'Brien and Connie Lyle. Although it does not contain an "instrument" as such, it does offer a list of items generated by self-advocates that can serve as a quality checklist. Sections include: "Things self-advocates say 'help' in services," "Things self-advocates say 'hurt' in services," and "Questions to ask in a service program evaluation." Available through the University of Oregon, Specialized Training Program, 135 Education, Eugene, OR 97403.

PART III

Annotated Bibliography of Measures
of Individual Integration

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MEASURE TITLE: Program Analysis of Service Systems:
Implementation of Normalization Goals (PASSING)

REFERENCE: Wolfensberger, W. & Thomas, S. (1983).
PASSING: Program analysis of service systems' implementation of normalization goals. Normalization criteria and ratings manual. (2nd Ed.). Toronto: NIMR.

DESCRIPTION: Forty-two ratings relating to social role valorization broken into settings, groupings and activities are described. Each rating is rated along a five level scale from "totally/disastrous" (Level one) to "excellent" (Level 5).

For purposes of this instrument, integration is defined as "the open participation of people with other people in culturally normative amounts, settings and activities." Social integration is defined as "participation by a (devalued) person or persons in social interactions and relationships with non-devalued citizens that are culturally normative both in quality and quantity, and that take place in normative activities and in valued, or at least normative settings and contexts." (p. 18). In PASSING, integration is directly measured by only six ratings. The balance of the ratings (e.g., the harmony of the setting and program with the neighborhood) address issues believed to be likely to be facilitate social integration).

PASSING can be applied equally to services as it can to individuals ("groupings" of one).

COMMENTS:

- PASSING requires extensive training to implement properly.
- It can be used as a total assessment (which is very thorough but also time consuming) or individual ratings only can be applied to a service/setting/program.
- It assumes that persons with disabilities should have valued roles within society.
- It measures a wide variety of aspects associated with "community integration/participation."

- MEASURE TITLE: Behavioral Observations and Relationship Rating Scales
- REFERENCE: Cole, D. A. (n.d.). Peer interaction programs for children with and without severe disabilities. University of Minnesota.
- DESCRIPTION: Behavioral measures. Uses time-sampling behavioral observations of 12 behaviors: appropriate play, cooperative play, watches play, requests toy, offers toy, rejects toy, assists/teaches, tolerates assistance, caretakes, positive emotion negative emotion.
- Relationship rating scales. Derived from the relationship rating scales developed by Pancake, Sroufe, Guess, Bayles & Miller. (1983). Relationship rating scales for preschools dyads. Unpublished instrument, Institute for Child Development, University of Minnesota, Minneapolis, MN, and Pancake, V. & Sroufe, L. A., (1984, July). Qualitative assessment of dyadic peer relationships in preschool: A new system of rating scales. Paper presented at the Second International Conference on Interpersonal Relationships, Madison, WI.)
- Five dimensions of relationships are measured (observed): symmetry, hierarchy, fun, engagement, and vitality.
- COMMENTS:
- Training is needed (e.g., videotaped sessions for interrater reliability).
 - Measures seem to apply to pairs only, and focus on school rather than residential settings. Still, the attention to relationships is potentially useful.

- MEASURE TITLE: A checklist of the most promising practices in educational programs for students with severe disabilities.
- REFERENCE: Meyer, L. (1985). A checklist of the most promising practices in educational programs for students with severe disabilities. Syracuse University, Division of Special Education and Rehabilitation.
- DESCRIPTION: Six categories reflecting program components are outlined: program philosophy, student opportunities for learning, IEP features, program characteristics, staff qualifications and accountability, and the adequacy of the facility. Each category consists of between 11 and 23 items.
- Each item is scored 0 (no evidence), 1 (some evidence) or 2 (clear evidence) according to the degree the issue is present in the service.
- COMMENTS:
- Checklist emphasizes the action aspect of integration.
 - Most items are self-explanatory, easy to use.

MEASURE TITLE: A severely handicapped integration checklist

REFERENCE: Stainback, W. & Stainback, S. (1983). A severely handicapped integration checklist. Teaching Exceptional Children. Spring, pp. 168-171.

DESCRIPTION: A checklist to estimate the degree to which severely handicapped students placed in regular schools are integrated into various regular school environments.

Contains 14 items concerned with environments such as the playground, lunchroom, hallways, and certain regular class activities.

Designed for elementary or secondary regular schools.

Completed by someone who is "intimately familiar with the activities of the severely handicapped students in the school."

Each of the 14 items are scored on a five-point Likert-type scale based on the percentage of severely handicapped students integrated into a school environment.

Total scores range from 0 to 56.

Described as a quick, easy, simple and objective instrument.

COMMENTS: - Measures the number of handicapped students engaged in an activity but not necessarily frequency/regularity or quality of the engagement.

- MEASURE TITLE: Interview schedule.
- REFERENCE: Crapps, J. M., Langone, J., & Swaim, S. (1985, June). Quantity and quality of participation in community environments by mentally retarded adults. Education and Training of the Mentally Retarded, pp. 123-129.
- DESCRIPTION:
- Observations and interviews were made of persons participating in the following: Fast food, Restaurant, Retail, Transportation, Leisure, Service to self (e.g., barber), Service to possessions (e.g., dry cleaner), and General service (e.g., bank).
 - Individuals are asked, in relation to each setting: how often they go to it ("not much" to "a lot"), who they go with, and if they need help ("not much" to "a lot").
 - Individuals are observed over at least a two-week period as to where and with whom they went and what they did.
 - "Quality" is measured by "with whom" (supervisors, peers, alone) and whether the person "needs help".

- MEASURE TITLE: 35-item survey of independent living and social integration activities.
- REFERENCE: Kregel, J., Wehman, P., Seyfarth, J., & Marshall, K. (1986). Community integration of young adults with mental retardation: Transition from school to adulthood. Education and Training of the Mentally Retarded, pp. 35-42.
- DESCRIPTION:
- Contains 35 items on independent living and social integration activities.
 - Areas investigated include: domestic, community, recreational and social activities.
 - Focuses on the fact of actual engagement in activities, without regard for the ability of the individual to engage/perform the activities.
 - Independent living: Basic Self Care (e.g., dressing), Home Management (e.g., meals), Mobility (e.g., rides a bicycle), Use of Community Facilities (e.g., restaurant), Use of Money (e.g., make change).
 - Social Integration Activities: Individuals With whom Time is Most Frequently Spent (e.g., Family), Social Activities Outside the Home (e.g., friends' homes), Recreation Activities (e.g., watch television), Sports (e.g., jogging), Events Attended regularly (e.g., sporting), Social Organizations and Clubs (e.g., YMCA).
 - Format: Forced choice yes-no or multiple choice.
- COMMENTS:
- No operational definition is offered for events participated in "regularly".
 - There is no indication of the time required to complete the survey.

- MEASURE TITLE: Official and unofficial participation in organization
- REFERENCE: Parker, R. N. (1983). Measuring social participation. American Sociological Review, 48, 864-873.
- DESCRIPTION: -A 22-item questionnaire to measure types of participation in organizations: official (7 items) and unofficial (15 items). Types of participation include: present and past offices in the organization; members of committees; chairpersons of committees; how many hours outside of meetings are spent on organizational activities.
- COMMENTS:
- Good literature review on the concept of social participation in sociology.
 - Not particular to persons with disabilities, but applicable to consumers of residential services.
 - Describes statistical procedures used in developing the various measurement models.

- MEASURE TITLE: The personal support system survey
- REFERENCE: Pearson, R. E. (1982). The Personnel and Guidance Journal, 61(2), 83-87.
- DESCRIPTION:
- Defines personal support system as "those persons whose presence or recollection we seek out because experiencing ourselves in relationship to them is a positive, personally enhancing force in our lives."
 - Describes the development of the survey instrument, i.e., the development of 13 categories of support, e.g., admiration, satisfaction, and factor analysis of the ratings of importance of each of the categories. Three factors were (a) Emotionally-Oriented Support, (b) Cognitively-Oriented Support, and (c) Idealized Support.
 - The categories can provide a framework for the exploration and analysis of clients' personal support status and resources both by the counselors and by the clients themselves.
- COMMENTS:
- The literature on personal supports seems worthwhile pursuing since high levels of personal support could be associated with high levels of community integration.
 - This survey is not mentioned in J. E. Pearson's (1986) review of five measures of social support, (Pearson, J. E. (1986). The definition and measurement of social support. Journal of Counseling and Development, 64(6), 390-395).
 - Not specific to people with disabilities.

- MEASURE TITLE: Life space structure
- REFERENCE: Lee, M. D. (1985). Life space structure: Explorations and speculations. Human Relations, 38(7), 623-642.
- DESCRIPTION:
- Describes four types of life space structure:
 - (1) home-based nuclear
 - (2) work-based nuclear
 - (3) conjoint
 - (4) diffuse
 - Optimally effective life space structure allows the individual to:
 - (1) Meet the most critical tasks in his/her life
 - (2) Achieve a satisfactory threshold of enjoyable or fulfilling experiences
 - (3) Avoid undue strain
- COMMENTS:
- See Lee (1985) Probing behavioral patterns of structuring daily life. Human Relations, 38(5), 457-476.
- Not specific to people with disabilities.
 - Could have interesting application to community integration of people with disabilities.

- MEASURE TITLE: Community adjustment scale
- REFERENCE: Seltzer, M. M., & Seltzer, G. (1978). Context for competence. (Available from Educational Projects, Inc., 22 Millard Street, Cambridge, MA)
- DESCRIPTION:
- Community adjustment is defined as: The regular and independent performance of mastered skills
 - The C.A.S. assesses mastery and performance of community activities in the following 8 areas:
 - (1) advanced personal care
 - (2) housekeeping
 - (3) communication
 - (4) social adjustment, e.g., recreational activities
 - (5) community participation, e.g., eating in public, travel
 - (6) economic management
 - (7) work
 - (8) agency utilization
 - Each area above has four domains: skill mastery; performance; opportunity and motivation
 - C.A.S. is administered by a social worker, house manager, parent or other supervisor of the "subject" in his/her residential setting.
 - Items are drawn from AAMD Adaptive Behavior Scale, Elwyn Institute, follow-up research, PAC, PASS, and PARC Project.
- COMMENTS:
- Some particular items, e.g., social adjustment (B-39f), community participation (B-45f) and agency utilization (B-60f) seem appropriate for measures of integration, others measure "adjustment" more than integration.

- MEASURE TITLE: ANDI: A normalization and development instrument
- REFERENCE: Flynn, A. G., and Weiss, S. T. (1977). ANDI: A normalization and development instrument. (2nd Ed.). (Available from the Authors; ANDI, P.O. Box 60964, Sacramento, CA, 95860)
- DESCRIPTION:
- Based on PASS (Wolfensberger & Glenn) and JCAH Accreditation Council for Mental Retardation and Developmental Disabilities.
 - Provides a "quick way of examining program strengths and areas needing improvement".
 - Training (certified) is required for official administration, although it is largely self-explanatory.
 - 15 areas cover: Program Rights, Social Integration, Facility and Administration.
 - Suitable for internal and external evaluation.
 - Integration related areas include:

Personal relationships	(8 items)
Integrated activities	(5 items)
Community resources	(8 items)
- COMMENTS:
- It is not clear how much time is saved compared to more comprehensive evaluations, e.g., PASSING.
 - The lack of specificity of item criteria suggests the possibility of a great deal of individual bias in scoring, and also difficulties in achieving team consensus.
 - As with PASS, many items examine areas believed to support integration, but no actually integrative in and of themselves, i.e., "positive interpretations".

APPENDIX A
THE COMMUNITY IMPERATIVE

**THE COMMUNITY IMPERATIVE:
A REFUTATION OF ALL ARGUMENTS
IN SUPPORT OF
INSTITUTIONALIZING ANYBODY
BECAUSE OF MENTAL RETARDATION**

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**THE COMMUNITY IMPERATIVE:
A REFUTATION OF ALL ARGUMENTS
IN SUPPORT OF
INSTITUTIONALIZING ANYBODY
BECAUSE OF MENTAL RETARDATION**

In the domain of Human Rights:

All people have fundamental moral and constitutional rights.

These rights must not be abrogated *merely* because a person has a mental or physical disability.

Among these fundamental rights is the right to community living.

In the domain of Educational Programming and Human Service:

All people, as human beings, are inherently valuable.

All people can grow and develop.

All people are entitled to conditions which foster their development.

Such conditions are optimally provided in community settings.

Therefore:

In fulfillment of fundamental human rights and

In securing optimum developmental opportunities,

All people, regardless of the severity of their disabilities, are entitled to community living.

A TIME TO TAKE SIDES

Every fundamental social change is accompanied by active, sometimes bitter debate and confrontation. The deinstitutionalization movement fits this mold. Some say deinstitutionalization is moving ahead too quickly. The data, they argue, do not warrant a wholesale abandonment of institutions for the retarded (Balla, 1978; Baumeister, 1978; Begab, 1978; Ellis et al., Memorandum, October 18, 1978, p. 16; Zigler, 1977, p. 52). Another professional research constituency has heralded community residences as morally and empirically preferable to the institutional model (Baker et al., 1977; Biklen, 1979; Blatt, 1973; Dybwad, 1979).

The ENCOR (Nebraska) and the Macomb/Oakland (Michigan) models of community services are two much heralded, notable examples of systems which have received government and community support. Like other efforts to establish community residences, these systems have experienced resistance, too. And in New York State and in the Washington, D.C. metropolitan area, prospective group homes have even been fire-bombed. But despite the occasional resistance, community residences are being established at a rapid rate.

In every time of profound social change people must take sides. Indecision, the failure to take sides, is tantamount to a political choice. On the institution question, or might we more accurately call it the community integration question, the time has long since come to take a stand.

THE CONTROVERSY

Pressures and justifications for continued institutionalization of retarded people abound. Despite recognition in most federal agencies that deinstitutionalization is a goal, social programs as frequently as not promote continued institutional services (Comptroller General, GAO, 1977). While the numbers of retarded persons institutionalized in mental retardation facilities have declined, the numbers of retarded people in nursing homes has increased in equal amounts (Conroy, 1977). Specialization of human services has been set forth repeatedly as justification for segregation. Virtually every state's education and developmental disabilities plan includes this reasoning. Institutions are being held out as appropriate placements for severely and profoundly retarded persons. Private and State economic interests make deinstitutionalization fiscally unprofitable, at least as

long as there is an absence of conversion plans for the existing institutional facilities (Blatt et al., 1977), something no state has developed. Local zoning ordinances continue to pose threats, albeit less and less effectively, to group living arrangements for retarded people in residentially zoned neighborhoods (City of White Plains v. Ferraioli, 1974). Some experts have seen the future of institutions and institutional abuse as so permanent and unshakeable that they have proposed euthanasia for more severely retarded persons (Heiffetz and Mangel, 1975). This line of reasoning is strikingly like the United States Marine policy of fire bombing Vietnamese villages to save them. And some states have released retarded people from institutions into proprietary homes and onto the streets, without providing any community adjustment services. Such policies seem almost conspiratorial, predictably, in their anger and disillusionment, some local communities have perceived deinstitutionalization as "dumping."

Our own view is that the principal barriers to deinstitutionalization are not technical ones. Federal program incentives can be redirected. Conversion plans can be fashioned. Exclusionary zoning laws can be and are being reshaped in courts and legislatures. And community support services can put an end to the practice of "dumping." But no amount of tinkering with technical planning matters alone can bring about community integration. The real issue, the prerequisite for making any kind of determination about whether or not to support deinstitutionalization, concerns how people view other people and, more specifically, how people classified as retarded are perceived. Policies of forcibly segregating groups of labeled people, whether for protection, punishment, or treatment, frequently reflect the possibility that the subject people have been devalued. In our culture, and in many others, institutions have provided the mechanism for large scale devaluation of certain identified groups, including the mentally retarded. As long as retarded people are socially, economically, and politically rejected, the institution will seem acceptable. But, forsake the devalued role and one must abandon a whole host of prejudicial and discriminatory treatments, the institutions among the most obvious of them.

By definition, institutions deny people community living experiences and limit the opportunities of nondisabled people to interact with their disabled peers. This fact exhibits quite clearly that the pivotal issues with respect of deinstitutionalization are not technical ones.

tionalization are moral — the society is richer, community life more rewarding when all people are valued, when people share in each others' lives — and legal — the constitution protects liberty — and not merely ones of differing treatment strategies. Thus, we do not make a case for community integration on the grounds that community living will always be more enriching or humane, in a clinical sense, than institutional settings, but rather on the grounds that integration is morally correct, that integration is basic to the constitutional notion of liberty, and that community programs inherently have far greater *potential* for success than do institutions.

It is probably fair to hypothesize that some people believe, simply as an article of faith, that retarded people should be segregated. That is, some people may hold this belief as a morally sound one, just as we hold the opposite view. Further, we can presume that the rationale for such a belief might be to protect the retarded, to protect "society," or both. At least these arguments have been raised historically, particularly during the eugenics era (Ellis, 1911). Today, arguments for institutional care are made largely on other grounds, mainly clinical ones.

Senior researchers, scholars, social planners, and decision makers have raised seven serious complaints against deinstitutionalization. Critics charge:

- that the allied concepts of deinstitutionalization, normalization, and educational mainstreaming are "little more than slogans . . . badly in need of an empirical base."
- that some people have such profound retardation that they cannot benefit from educational programming at all and certainly not from community placement. They call for "enriched" custodial care in an institutional setting;
- that the community is not prepared to accept the profoundly and severely retarded and probably never will be;
- that there is no evidence that retarded persons develop more in non-institutional settings;
- that there can be good and bad institutions and good and bad community settings. They argue that neither form of service is inherently bad or good;
- that institutions are a more efficient and less expensive way to provide services, particularly to people with severe and profound retardation;

- that current public policy toward deinstitutionalization is part of a historical swinging pendulum. By this line of reasoning, institutions will become fashionable and favored again, after the community thrust has run its course and experienced failure.

Interestingly, when we move beyond the ideological, moral, and legal bases for community integration, that is when we examine the sociological, psychological, and economic research on institutions and community services we find that what we consider to be right is also best. The available research supports community integration.

Observational data on institutions have revealed shocking evidence of human abuse, in the form of retarded persons forced to live in isolation cells, showers, and barren dayrooms, people washed down with hoses like cattle in a slaughter house, people tied to benches and chairs and constrained in straight jackets, toilets without toilet seats and toilet paper, or stall walls, broken plumbing, cockroaches, unclothed people burned by floor detergent and overheated radiators, people intentionally burned by their supervisors' cigarettes, rooms crowded wall to wall with a sea of beds, children locked in so-called "therapeutic" cages, people forced to eat their meals at breakneck speeds, food provided in unappetizing form (often as mush), and people drugged into quiescence. Observational data repeatedly reveal these and a range of other equally abusive phenomena (Biklen, 1973; Blatt and Kaplan, 1966; Blatt, 1970, 1973; Blatt, McNally, and Ozolins, 1978; DeGrandpre, 1974; Giles, 1971; Holland, 1971; N.Y.A.R.C. et al. v. Rockefeller, 1972; Wooden, 1974; Halderman v. Pennhurst, 1977, and Wyatt v. Hardin, 1971; Taylor, 1977, and Wiseman, 1969). The recent parade of court cases involving issues of institutional life provides another unequivocal source of data devastating to institutional legitimacy (N.Y.A.R.C. et al. v. Rockefeller, 1972; Wyatt v. Hardin, 1971; Halderman v. Pennhurst, 1977).

Even the most modern institutions have fostered routinization and other forms of institutionalization of residents' lives (Blatt, McNally, and Ozolins, 1978). In fact, routinization, degradation, and human devaluation, though not always of a violent, cruel, or unusual nature, seem to be endemic to institutional environments (Goffman, 1961; Vail, 1966; Dybwad, 1970).

One argument frequently proposed in defense of institutions is that abuses result from unsensitive and ill-trained or ineffectual staff. This hypothesis is overwhelmingly refuted by the breadth of data

available on the institutional context as a determinant of staff behavior (Zimbardo, 1973; Goffman, 1961; Taylor, 1977).

Another belief frequently used to buttress the besieged institutions holds that underfinancing creates the circumstances for abusive institutional conditions. Yet, institutions have proven to be the most expensive form of "service" for retarded persons. As the Pennhurst, Plymouth and Willowbrook experiences attest, even those institutions where states are expending between \$35,000 and \$45,000 per resident annually and which have some of the most favorable staffing ratios do not adequately protect their residents from physical and psychological harm or provide even minimally adequate habilitation to clients (Gilhool, 1978; Ferleger, 1979; MARC et al v. Donald C. Smith, M.D. et al). Higher ratios of professional staff and centralized professional services do not seem to improve the quality of services either (McCormick, Zigler, and Balla, 1975).

What else do we know about institutions? We know that interaction between institutionalized clients and other people, either other clients or treatment staff, drops substantially in the institutional environment (Goffman, 1961; Provence and Lipton, 1962, and Giles, 1971). We know that institutions are more often than not unstimulating environments (Flint, 1966). We know that institutionalized residents are not likely to be cared for by a few "primary" caretakers, but by hundreds of different staff over a two or three year period (Hobbs, 1975). We know that institutionalized children frequently become apathetic and isolated (Hobbs, 1975) or overly anxious to gain recognition and attention (Yarrow, 1962). Within just a few hours of entering an institution, residents tend to become dramatically less normal, both in appearance and in interaction with others (Holland, 1971). We know that institutional life can promote perseveration behavior. We know that the people who seem to benefit most from institutions are those who came from what clinicians have regarded as the worst home situations (Zigler and Balla, 1976). In other words, the institution was a relatively positive experience only in relation to more miserable pre-institutional experiences. And we know that people who have been institutionalized for long periods of time become more imitative and more conforming (Zigler and Balla, 1977). We know too that institutions can help infants learn to be non-ambulatory (DeGrandpre, 1974). Ironically, some critics of total deinstitutionalization have themselves reported an inverse

relationship between institutional size and quality of care. Institutions with smaller living units are superior to those with larger ones and most importantly, group home residences of 10 residents or less, in the community, tend to be more resident oriented (Zigler and Balla, 1976; and McCormick, Balla and Zigler, 1975). Further, a comparison of severely handicapped children in institutional and small community settings provides substantial evidence of greater skills development among clients in the small community settings (Kushlick, 1976; Tizard, 1969).

While an argument has been made that for severely and profoundly retarded persons the institution is a less expensive mode of service than community residences (Zigler, 1978), data have not been provided to substantiate that claim. In fact, available information indicates that if there is a difference, institutions are a more expensive though less effective mode of service (McCormick, Balla and Zigler, 1975). A study of the cost of services for 362 ex-residents of the Willowbrook Institution found a savings of at least 50% and 68% of the subjects were classified as severely and profoundly retarded (N.Y.S. Department of Mental Hygiene, N.D.). Similarly, Judge Broderick found that it cost \$60 per day to keep people in disgraceful conditions at the Pennhurst institution and one third that amount to provide community living arrangements (Halderman v. Pennhurst, 1977). In each of the available studies, it is fair to conclude that there are no "economies of scale" in residential services (Piasecki, et al., 1978; O'Connor and Morris, 1978; Murphy and Dattel, 1976; Jones and Jones, 1976 and Mayeda and Wai, 1975). If there are differences to be seen, those can best be described as an inverse economics of scale; smaller is less expensive.

Historically, it has been argued, institutions were developed in 19th century America as a response to the failure of communities to meet the needs of the retarded. This is only partially true. It is true that Dix, Howe, Wilbur, Segun and others formulated the earliest institutions in response to community failure, but the failure was an absence of programs and services and *not a failure of actual community services*. Shortly thereafter, at the turn of the century, large institutions came into being, and not so much as products of benign motives. The latter institutions and the then emerging institutional model were largely a response to perceived social problems created by urbanization and immigration. Their purpose was to isolate the retarded from society. So there is no objective

truth to the claim that we are witnessing the swing of a pendulum, back to a community service model which once, a century ago, failed us. We have never fully explored the potential of community services.

Another argument frequently used to justify institutions hinges on the claim that some people are so retarded that they cannot benefit from educational programming. This thesis has been used to justify "enriched" custodial care in institutions (Ellis et al, 1978). Yet, only if education is artificially limited to academic training can it be argued, as some have, that not all people will benefit from it. We know that all people can benefit from educational or habilitative programming. This conclusion has been drawn by major proponents of community integration (Blatt and Garfunkel, 1969; Dybwad and Dybwad, 1977; *PARC v. Commonwealth of Pennsylvania*, 1971), as well as by some who have advocated a continued institutional role (Baumeister, 1978; Zigler, 1978).

Critics and proponents of deinstitutionalization do agree that there are both "good" and "bad" institutions and "good" and "bad" community residences. That is, those on either side of the controversy can point to abusive institutions, relatively "good" institutions, bad community settings and good community settings. But, therein ends the agreement. As proponents of deinstitutionalization, we reject the view that good and bad settings will occur equally as frequently in communities as in institutions so long as state involvement remains relatively constant. We believe that institutions have a propensity to spawn abuse. We further believe that community settings have inherently greater potential to afford humane, individualized, and appropriate treatment.

Further, we believe that even so-called "good" institutions can be good only in a clinical sense. Residents may receive competent, even imaginative, educational/habilitative programming. But, the very existence of the institution must be viewed as a failure. Here we must refer to the earlier examination of moral and constitutional rights. Institutions, by definition, limit retarded people from interaction with non-disabled people and lure retarded people from community living. That is not to say that we, nor anyone else, can justify "dumping" retarded people into communities. Further, we expect and know that retarded people may have difficulties in adjusting to community life. To this our response should be not to eliminate the problem (by institutionalizing

people) but to help people solve those problems.

Data on community programming support the view that whereas abuses in institutions are to be expected, abuses in community programs are more the exception than the rule. First hand accounts, for example, indicate that deinstitutionalized retarded persons generally are happy or happier about their lives in the community (Edgerton and Bercovici, 1977; Bogdan and Taylor, 1976; Gollay et al., 1978). Moreover, when given an option to stay in the community or return to the institution, well over 75% of those placed in foster homes, group homes, and adult homes would stay in the community (Scheerenberger and Felsenthal, 1976). Further, the data on community adjustment, by whatever standards are applied, yield a consistent pattern of moderate though unpredictable success (Baller, Charles, and Miller, 1966; Edgerton and Bercovici, 1976; Cobb, 1972; Bogdan and Taylor, 1976; Kennedy, 1976; Muelberger, 1972; O'Connor, 1976; and Gollay et al., 1978).

The complement to adjustment is acceptance. Is it fair to say that retarded people, particularly the more severely and profoundly retarded, will not be accepted in communities? No. Despite some instances of violence and other forms of resistance, the history of retarded people in the community is a history of acceptance. In fact, the majority of all retarded people, including the most disabled, have always lived in the community, with their own families and have found considerable acceptance (Saenger, 1957). And charges that the retarded are more likely than others to commit criminal acts are entirely without foundation (Biklen and Mlinarcik, 1978). Even the allegations that property values decline when group homes and other home-like living arrangements for the retarded are located in residential neighborhoods has been proven false (Thomas, 1973, N.Y. State Office of Mental Retardation and Developmental Disabilities, 1978). Finally, if some retarded people find resistance and hostility in the communities, the fair response is hardly to punish retarded persons (by institutionalizing them) for others' ignorance.

CONCLUSION

The data on institutions and community programming do not equivocate. Institutions have little with which to defend themselves. Community integration seems, in every respect, preferable. Indeed, we ask, when is it time to express

one's moral beliefs? When is it time to enforce constitutional rights? And when is there enough data to support a fundamental social change? At what point must we cease to ask "does it work?" and instead ask "how can we help make it work?"

Even if the data were less clear, even if there were no data to support either side of the controversy, institution vs. community integration, we would support the latter. We make the determination on moral and constitutional grounds.

We believe that all people, however severe their disabilities, must be permitted opportunities to live among their non-disabled peers and vice versa. We believe that people who have been classified as retarded should have available to them the patterns and conditions which characterize the mainstream of society. Indeed, we believe that support services should be available to promote the fullest possible integration of people with disabilities into communities.

To allow for continued segregation of retarded persons into institutions and other forms of residential ghettos can only lend credence to the many fears of, and myths and prejudices against people with disabilities. And no amount of scientific language can mask the fact that segregation benefits no one. We find no reasons, either based in data or moral belief, to support the practice of isolating or segregating retarded persons from the mainstream of communities. If people need services, let them receive them in typical communities. Rational scientific inquiry and moral convictions can support no other conclusion.

The issue of institutionalization, like the issues of slavery and apartheid, strikes at the very core, the very essence of our common humanity. Just as the emergence of Jim Crowism, the Ku Klux Klan, and racist theories of black inferiority do not and cannot justify the conclusion that Black Americans were better off under slavery, neither can neighborhood resistance, exclusionary zoning codes, expert claims that some people cannot learn, or even firebombing of prospective homes combined to justify the conclusion that mentally retarded people are better off in institutions. What is at issue here is fundamental human rights and the quality of the lives of human beings. To claim that some people cannot learn, to place those same people in isolated institutions, and then to suppose that the dignity and well being of those people can be protected, let alone enhanced, is to deny history. And to suggest that some people cannot and should not live amongst their fellow human beings is to deny our shared humanness.

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APPENDIX B
A STATEMENT IN SUPPORT OF FAMILIES

A STATEMENT IN SUPPORT OF FAMILIES AND THEIR CHILDREN

THESE PRINCIPLES SHOULD GUIDE PUBLIC POLICY TOWARD FAMILIES OF CHILDREN WITH DEVELOPMENTAL DISABILITIES...AND THE ACTIONS OF STATES AND AGENCIES WHEN THEY BECOME INVOLVED WITH FAMILIES:

All children, regardless of disability, belong with families and need enduring relationships with adults. When states or agencies become involved with families, permanency planning should be a guiding philosophy. As a philosophy, permanency planning endorses children's rights to a nurturing home and consistent relationships with adults. As a guide to state and agency practice, permanency planning requires family support, encouragement of a family's relationship with the child, family reunification for children placed out of home, and the pursuit of adoption for children when family reunification is not possible.

Families should receive the supports necessary to maintain their children at home. Family support services must be based on the principle "whatever it takes." In short, family support services should be flexible, individualized, and designed to meet the diverse needs of families.

Family supports should build on existing social networks and natural sources of support. As a guiding principle, natural sources of support, including neighbors, extended families, friends and community associations, should be preferred over agency programs and professional services. When states or agencies become involved with families, they should support existing social networks, strengthen natural sources of support, and help build connections to existing community resources. When natural sources of support cannot meet the needs of families, professional or agency-operated support services should be available.

Family supports should maximize the family's control over the services and supports they receive. Family support services must be based on the assumption that families, rather than states and agencies, are in the best position to determine their needs.

Family supports should support the entire family. Family support services should be defined broadly in terms of the needs of the entire family, including children with disabilities, parents, and siblings.

Family support services should encourage the integration of children with disabilities into the community. Family support services should be designed to maximize integration and participation in community life for children with disabilities.

When children cannot remain with their families for whatever reason, out-of-home placement should be viewed initially as a temporary arrangement and efforts should be directed toward reuniting the family. Consistent with the philosophy of permanency planning, children should live with their families whenever possible. When, due to family crisis or other circumstances, children must leave their families, efforts should be directed at encouraging and enabling families to be reunited.

When families cannot be reunited and when active parental involvement is absent, adoption should be aggressively pursued. In fulfillment of each child's right to a stable family and an enduring relationship with one or more adults, adoption should be pursued for children whose ties with their families have been broken. Whenever possible, families should be involved in adoption planning and, in all cases, should be treated with sensitivity and respect. When adoption is pursued, the possibility of "open adoption," whereby families maintain involvement with a child, should be seriously considered.

While a preferred alternative to any group setting or out-of-home placement, foster care should only be pursued when children cannot live with their families or with adoptive families. After families and adoptive families, children should have the opportunity to live with foster families. Foster family care can provide children with a home atmosphere and warm relationships and is preferable to group settings and other placements. As a state or agency sponsored program, however, foster care seldom provides children the continuity and stability they need in their lives. While foster families may be called upon to assist, support, and occasionally fill in for families, foster care is not likely to be an acceptable alternative to fulfilling each child's right to a stable home and enduring relationships.

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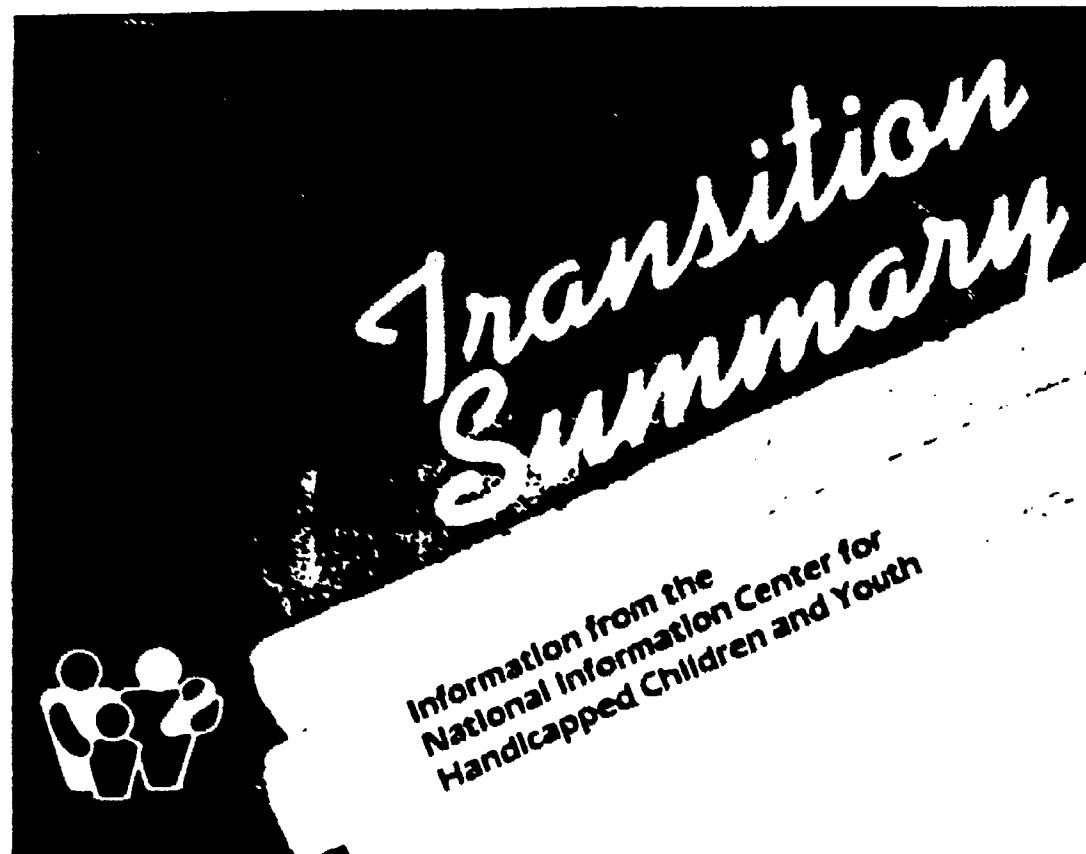
APPENDIX C

MAKING SURE A HOUSE IS STILL A HOME

Making Sure a House Is Still a Home

By Hank Bersani, Jr.

In the State of Ohio, as in virtually every state in the country, there is a growing trend to move people with mental retardation from state institutions into less restrictive residential settings. The Ohio Association for Retarded Citizens (ARC-Ohio), like many other parent organizations, has been supportive of this trend. However, at the same time, as an advocacy organization, there was concern that the community placements which people were moving into were of mixed quality. The concerns led the organization to develop a parent-based project to monitor the quality of residential placements.



MARCH

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Who Currently Monitors Residential Services?

As it turns out, there are many answers depending on where one lives. Homes that are funded by Medicaid, such as Intermediate Care Facilities for the Mentally Retarded (ICFs/MR), are administratively approved and reviewed by the Health Care Financing Administration (HCFA). Other programs that are fully or partially funded by state offices of Mental Retardation and Developmental Disabilities are usually reviewed by them. Residences are "checked on" for fire safety by local fire authorities. Most programs have staff who are charged with some responsibility to safeguard quality: case managers, program coordinators, house managers, and so on. Many residences are also certified by such bodies as The Commission on Accreditation of Rehabilitation Facilities, Accreditation Council for Services for Mentally Retarded and other Developmentally Disabled Persons, and The Joint Commission on Accreditation of Hospitals. Family members and neighbors who visit on

a regular basis can be said to be monitoring the quality of care in the program.

As in other states, residences in Ohio are already monitored by several agencies. Some of the programs experienced additional program reviews as a part of a consent agreement from a class action lawsuit over conditions in state institutions.

Why is There a Need for Additional Monitoring?

At first glance, one might assume that there was more than enough monitoring in place already. However, ARC-Ohio determined that this was not the case. We felt there was a great need for an additional type of monitoring for two reasons. First, existing safeguards were clearly insufficient because poor conditions existed in several residences across the state. ARC-Ohio is dedicated to the position that deinstitutionaliza-

tion can succeed, and that problems in existing homes should be seen as failures in implementation, rather than failures of the concept. Second, existing monitoring efforts were of a limited scope. Most forms of monitoring are formal, and reflect the concerns, assumptions and points of view of professionals. While these approaches have their value, ARC-Ohio, as a parent advocacy organization, has an equal concern for the perspective of family members, and the point of view that develops from a non-professional involvement. ARC-Ohio determined the need for a parent advocate oriented monitoring approach that could augment (not supplant) existing monitoring efforts. The need was for a method that was formalized enough to be useful, but not so routinized that it amounted to a checklist of only the most mechanical concerns (number of toilets, temperature of water at the tap, etc.). These matters can be quite important but should be adequately handled by formal, professional review.

"Concerned parents, family members, and friends already have the two major qualifications to be monitors: they are well aware of what it means to live successfully in a home in the community and they have the unique perspective that is lacking in existing systems."

Why Are Parents/Advocates an Important Resource for Monitoring Residences?

Concerned parents, family members, and friends already have the two major qualifications to be monitors: they are well aware of what it means to live successfully in a home in the community and they have the unique perspective that is lacking in existing systems. If necessary, a group of parents/advocates could set out to monitor community residences with little or no support, and make a significant impact on the quality of the service system. However, with the support of a small grant from Miami University in Oxford, Ohio, ARC-Ohio developed a schema for a statewide, parent-based, residential monitoring project. It is a model that we feel can be easily replicated in other states across the country.

What Were The Basic Goals of The Project?

We began by identifying the following four goals:

- 1) To assess both the strengths and weaknesses of community residential programs;
- 2) To provide statewide feedback on how services are delivered by providers, and received by individuals who live in the residences;

- 3) To develop a constructive method by which citizens and service providers can work together to improve the services to persons with mental retardation; and

- 4) To ensure that persons who experience mental retardation have the opportunity to live in community settings which accommodate their individual needs with a minimum of restriction.

In line with our goals, we decided there were two tools that needed to be developed to help the monitors do their jobs:

- 1) A uniform monitoring instrument composed of open-ended questions based on a set of philosophical statements.

- 2) Additional written support materials, compatible with the evaluation instrument, which contain basic information about residential services.

ARC-Ohio has published an evaluation instrument, *Monitoring Residential Services: Guidelines*, and a companion volume of support information, *Monitoring Residential Services Handbook*. The *Guidelines* addresses major areas of residential quality, followed by several dozen open-ended questions which address each of these areas.

Rights. Human, civil and legal rights are held by all persons. These rights are not forfeited merely by living in a community residence. Service providers are obligated to respect and protect all aspects of the rights of the people who live there. Residential services have added obligations to *teach* people about their

rights and to *assist* them in the daily exercise of their full range of rights.

Environment. First and foremost, a community residence is a home. Its function as a "program," "service" or "agency" is clearly secondary. Efforts must be made to create a physical and social environment which is "homelike," comfortable, and which asserts the humanity of the people who live there. The residence should not draw any undue attention to the location or the people who live there.

Staff. Direct care staff are the individuals who actually provide the service received by the people who live in the residence. Because staff may care for people whose needs are quite challenging, they must be well trained, well supported, and well supervised.

Commitment to Personal Growth. A community residence must provide needed supervision and support in an environment which also allows opportunities for growth and development through a variety of experiences. By assuming the responsibility to provide a residential service, an agency and its staff also accept the obligation to provide a diverse range of living and learning experiences. These experiences must include a *normative* amount of exposure to *reasonable* levels of risk. Learning occurs in an environment with manageable failure and meaningful successes.

Use of Community Resources. Although living near resources is desirable, it is even more important that those resources be *used*. The people living in a community residence must have systematic opportunities to use community resources on a regular basis. Resource use should be in small groups (1 or 2) whenever possible. Each individual should experience a *variety* of community experiences appropriate to his/her age and interests. The residential provider is required to demonstrate a commitment to the *normalizing* use of community resources and community participation for all people who live in the home.

The instrument focuses on the fact that community residences are first

and foremost homes. The job of the parent monitor is to assess the quality of a home, rather than a "facility" or a "program." The monitoring visit is focused on identifying indications that the house may not be a home. We offer our monitors the following guidelines:

First, tour with empathy. Think of the residence, not as a "place for them," but as a home for someone like you. Ask yourself "If I lived here what would I want?"

Second, focus on the conditions you see rather than the excuses for those conditions. If you see something wrong, an invasion of privacy for example, focus on that fact from the point of view of a person living that experience. Then, the "reason" that there is not sufficient staff to offer privacy is not an acceptable "excuse." It may be a practical reality, but if parent monitors do not speak up, do not expect anyone else to.

Third, use your own living arrangements as a standard. This does not mean that we all have to live in the same kinds of houses, or put up with each other's taste. It does mean, however, that a residence that is "better than where they lived before," or one that is "good . . . for a group home," is not good enough.

What Is the Ultimate Role of a Monitor?

Many of us have been brought up with the old cliché that you should not criticize something unless you have a solution. I no longer believe that, and I feel that it represents an attitude that is detrimental to the exercise of parent-based monitoring. We need to think of a monitor as a smoke detector. Its job is to keep watch, and sound an alarm if there is a possibility of a problem. Smoke detectors occasionally sound false alarms. Burned popcorn or dust may set them off by accident. But we do not expect them to put out the fire they warn us about, and we tolerate false alarms, because they are far better than not being alerted to a dangerous situation. Monitors may have concrete solutions to problems

"We need to think of a monitor as a smoke detector. Its job is to keep watch, and sound an alarm if there is a possibility of a problem."

they identify. If they do, so much the better. But this is not a prerequisite to criticism.

It is important for everyone involved in the monitoring process to understand what it can and can not do. Such monitoring is not intended to take the place of administrative supervision licensure or certification. The presence of a volunteer-based monitoring project does not relieve officials from their statutory responsibilities to supervise care and ensure quality. Our monitoring project is designed specifically to support and enhance existing residential safeguards. It is not intended to supplant governmental supervision. It is our belief that all of the existing safeguards and monitoring approaches are needed in addition to private, voluntary, parent and citizen-based efforts.

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APPENDIX D

INSURING QUALITY SERVICES

Reprinted from:

Taylor, S. J., Racino, J. A., Knoll, J. A., & Lutfiyya, Z.
(1987). The nonrestrictive environment: On community
integration for people with the most severe disabilities.
Syracuse, NY: Human Policy Press. 89-91.

Insuring Quality Services

The question of insuring quality services is a particularly critical one for a widely dispersed system of small, more individualized services. From integrated job placements to specialized foster care to in-home respite to supportive living, a variety of methods are necessary to insure continued service quality.

The ideas and practices described in this section involve a wide range of actors (e.g., parents, consumers, direct services staff, advocates, volunteers, professionals) and a wide range of techniques. At a minimum, a mix of external and internal safeguards together with input from a variety of actors is essential to insuring quality services.

How can I insure service quality?

- * Develop and fund a community monitoring group consisting of parents, consumers and interested citizens to look at quality of life issues in existing community homes.
- * Develop "cluster groups" (e.g., residential, rehabilitation) consisting of area service providers, parents, consumers and interested citizens to review proposed services in-depth and to promote sharing amongst providers.
- * Develop a regular comprehensive systems review process that focuses on people and programs as well as paperwork, that includes feedback from staff, consumers and parents, and that is both summative and formative in nature.
- * Develop a Program Ethics Committee to review all research proposals and programs that might potentially restrict client rights, and to investigate instances of abuse and neglect; include all external people on the committee (e.g., parents, consumers, community members, attorneys, university specialists).
- * Develop a Client Advisory Board that consists of representatives from all area agencies and reports directly to a regional management team.

- * Implement a regular process of external review other than professional peer reviews and audits for compliance (e.g., citizen evaluation using Program Analysis of Service Systems).
- * Actively encourage the development of self-advocacy efforts, including funding for independent advisors.
- * Develop a range of internal mechanisms for maintaining quality.
 - written grievance procedures for staff and consumers
 - regular review of paperwork, record-keeping and safety/health standards
 - annual consumer surveys
 - unannounced peer reviews within agency
 - annual establishment and review of goals and objectives by each department/team
 - quality circles involving voluntary employee participation in decision-making and problem-solving
 - clear philosophically-based mission statement.
- * Encourage and support the involvement of parents and consumers on agency boards. Encourage board members to visit and spend time in homes/vocational sites.
- * Implement a centralized case management system that is separate from direct service provision; have unannounced visits to homes during evening and weekend times.
- * Encourage the input of neighbors; develop neighborhood advisory boards; foster the development of relationships between disabled and non-disabled people.
- * Establish a semi-autonomous or autonomous agency to monitor service quality in the community-based programs.
- * Conduct follow-up interviews or questionnaires on a random sample of "consumers" to track their satisfaction; use case-workers, students, board members and volunteers.
- * Use a self-evaluation manual; develop a work group comprised of representatives from all levels of an organization (i.e., board of directors, agency administrators and staff) and from outside the organization (i.e., parents, consumers, interested citizens) to adapt the methodology to your own place.
- * Use a private evaluation service consultant to assist in designing a quality assurance system.

* Obtain and read:

- Apolloni, T., Meucci, S., & Triest, G. (1981). Monitoring the quality of life experienced in living arrangements: A guide to citizen participation. Sacramento, CA: California State Council on Developmental Disabilities.
- Bersani, H. A. (1984). Monitoring community residences: Guidelines & handbook. Columbus, OH: ARC Ohio.
- Bradley, V. J. (1984). Assessing and enhancing the quality of services: A guide for the human service field. Cambridge, MA: Human Services Research Institute.
- Gardner, J. F., Long, L., Nichols, R., & Iagulli, D. M. (Eds.). (1980). Program issues in developmental disabilities: A resource manual for surveyors and reviewers. Baltimore, MD: Paul H. Brookes.
- Williams, P., & Shoultz, B. (1984). We can speak for ourselves: Self-advocacy by mentally handicapped people. Bloomington, IN: Indiana University Press.